

Developing Evidence Based Social Care Policy & Practice

Part Three

Feasibility of Undertaking Systematic Reviews in Social Care

Andrew F Long

Mary Godfrey

Tracy Randall

Alison Brettle

Maria Grant

DEVELOPING EVIDENCE BASED SOCIAL CARE POLICY AND PRACTICE

PART THREE

FEASIBILITY OF UNDERTAKING SYSTEMATIC REVIEWS IN SOCIAL CARE

2002

Research Team

Professor Andrew Long¹
Mary Godfrey²
Tracy Randall²
Alison Brett¹ (till October 1998)
Maria Grant¹ (from October 1998)

¹ Health Care Practice R&D Unit, University of Salford

² Nuffield Institute for Health, University of Leeds

Bibliographic Details:

Long AF, Godfrey M, Randall T, Brett AJ and Grant MJ (2002) *Developing Evidence Based Social Care Policy and Practice. Part 3: Feasibility of Undertaking Systematic Reviews in Social Care*. University of Leeds (Nuffield Institute for Health) and University of Salford (Health Care Practice R&D Unit).

CONTENTS

	Page
Executive Summary	i
Chapter 1 Introduction	1
Chapter 2 Pre-Requisites for the Review Process	3
The Guiding Question	3
Translating Policy Questions into Researchable Questions	4
Chapter 3 Searching for Evidence	9
Overview of Approach	9
Exploring for Overlap	12
Chapter 4 Evaluating the Evidence	15
Developing Evaluative Tools to Critically Appraise the Evidence	15
Applying the Evaluative Tools to the Retrieved Studies	17
Chapter 5 Synthesising the Evidence	19
Overview of Approach	19
Identifying Possible Policy Implications	20
Chapter 6 Conclusions	23
References	26
Appendix One Selected Search Strategies	27
Appendix Two Evaluative Tool for Quantitative Studies	30
Appendix Three Evaluative Tool for Qualitative Studies	34
Appendix Four Example Completed Evaluative Tool for a Quantitative Study	38
Appendix Five Example Completed Evaluative Tool for a Qualitative Study	43
Appendix Six Checklist to Evaluate an Outcome Measure	48

EXECUTIVE SUMMARY

Funding was provided under the *Outcomes of Social Care for Adults* initiative (198/1021). A feasibility study was to be undertaken towards establishing a 'review policy capacity' to support the development of a research/evidence based culture in social care policy and practice. This was to be taken forward by undertaking systematic review work in two topic areas.

This report explores the issues faced in undertaking the feasibility study as they arose in the two substantive reviews, and ways that they were overcome. Insight is provided into the prerequisites for the review process and the review process itself.

1. Pre-Requisites for the Review Process

A critical pre-requisite for such review work is the guiding question. The research team defined this as follows:

'What interventions and associated mix of service and professional practices produce best outcomes, from a range of stakeholder perspectives?'

This recognises that interventions in social care are complex. It also questions the taken-for-granted definitions of success / outcome by drawing explicit attention to the need to explore the perspectives of all key stakeholders.

Seemingly simple policy level questions (for example, do preventive services for older people work?) need to be translated into researchable questions. This will involve a considerable amount of initial conceptual and literature scoping work. The challenge is to achieve a balance between defining the topic in a clear and concise manner to enable systematic coverage, whilst ensuring that the core questions are meaningful and relevant to policy and social care practice.

2. Searching for Evidence

Thorough and comprehensive ways of searching electronic databases for the various research designs were developed. The overall approach involves a multi-layered approach, moving backwards and forwards through the stages of scoping, refinement and confirmation. This process needs to take place alongside the refinement of the inclusion and exclusion criteria.

It is essential to search across multiple, rather than a single, databases. For both topic areas, there was a relatively small overlap between databases. This suggests that users of systematic reviews need to query the range of databases searched and any restriction of the search to one or another database. Careful thought must be given to the most appropriate database to search to prevent missing vital information and possibly influencing the results of the review. The search strategies must be made explicit, including the specific search terms, databases searched and not searched.

3. Appropriate Evidence Bases

In order to gain insight into the complexity of interventions in the social care field and the perspectives of service users and their informal carers, systematic reviews must include evidence from both quantitative and qualitative research studies.

4. Evaluating the Evidence

The review and synthesis of evidence arising from multiple research designs necessitated the development of two evaluative templates, one for qualitative and another for quantitative research designs. The developed evaluative tools provided an effective way to critically appraise and summarise the studies. The development work has also demonstrated the feasibility of systematically appraising qualitative research studies.

5. Outcome Measurement

The review work for both topic areas illustrated the dearth of attention to the outcome criteria that users and their informal carers might see as relevant. Further research is needed to address this, undertaken in partnership with users.

6. Synthesis of Evidence

While greater weight must be placed on well designed and executed studies that enhance understanding over cause and effect (attributive confidence), the primary consideration must be the nature of the research question. This leads to the inclusion of other factors in judging the overall contribution of the evidence. Five criteria were identified: relevance of the study to the aims of the topic area review; the detail provided on the nature of intervention; the relevance of the outcome criteria and measures; the sufficiency of the follow-up period; and the degree of methodological strength/control of sources of bias. In addition, it is essential to make the review process as ‘transparent’ as possible.

In conclusion, this study has demonstrated the feasibility, and complexity, of undertaking systematic reviews of policy level questions in social care.

CHAPTER 1

INTRODUCTION

Funding was provided under the *Outcomes of Social Care for Adults* initiative (198/1021). A feasibility study was to be undertaken towards establishing a 'review policy capacity' to support the development of a research/evidence based culture in social care policy and practice. This was to be taken forward by undertaking systematic review work in two topic areas. These were agreed to cover the areas of community based rehabilitation services for adults with severe mental illness and preventive services for older people.

Two major rationales underpinned the research work. Firstly, it was important to clarify the feasibility of undertaking systematic reviews that drew on both high quality quantitative, causally-oriented research and qualitative studies which placed a high priority on the context, meaning and perceptions of participants to the particular interventions. Secondly, it was valuable to learn from and build on the experience in the health care sector, for example, the work of the Cochrane Collaboration and the NHS Centre for Reviews and Dissemination. In particular, in contrast to the health care sector, the Universities of Salford and Leeds research team proposed that an integrated approach to the development of evidence based social care was appropriate. This was to draw together review work on both what works (effectiveness) and the success criteria (outcomes) of the multiple participants in a social care context.

For the purpose of this study, the notion of feasibility was broken down into a number of component questions:

- Can policy level questions in the social care field be translated in a sufficiently reliable way to enable the search and location of relevant evidence?
- Is there an existing social care evidence base of sufficient quantity and quality to review?
- Can evidence from a range of quantitative and qualitative studies be rigorously evaluated?
- Are the outcome criteria relevant to the perceptions of users and carers?

- Is it possible to synthesise evidence from a range of study types to inform the underlying policy debate?
- Can the findings of policy level reviews also inform the practice of social care?

This part of the final report to the Department of Health addresses the issues faced in undertaking the feasibility study as they arose in the two substantive reviews, and ways that they were overcome. It provides insight into the prerequisites for the review process, in particular, the necessary conceptual and theoretical work to enable the undertaking of the review and the review process itself. The aim is to clarify what makes it 'more' or 'less' feasible to undertake systematic review work of research literature on effectiveness and outcomes in social care. It concludes by drawing out key features for the undertaking of systematic review work to inform both policy making and social care practice.

CHAPTER 2

PRE-REQUISITES FOR THE REVIEW PROCESS

The Guiding Question

The single and most critical defining feature of a systematic review in social care is the core question driving the process. In this research, we defined this as follows:

'What interventions and associated mix of service and professional practices produce best outcomes, from a range of stakeholder perspectives?'

This broadens the seemingly simple, 'does it work?' question in two critical ways.

Firstly, it recognises that interventions in social care are complex. They commonly comprise multi-dimensional components and are provided by a range of professionals and staff practices in a variety of organisational settings. Most particularly, the intervention involves multi-professional input over time. It thus becomes highly problematic to identify 'which bit' has 'what particular effect,' as perceived 'by whom'. It becomes essential to understand what an intervention actually is within a social care context.

Secondly, it questions the taken-for-granted definitions of success / outcome, by explicitly drawing attention to the need to explore the perspectives of all key stakeholders. Most particularly, in social care (and only more recently in the health care area), this requires giving priority to the perspective of service users and their informal carers. Indeed, it is the outcome criteria of service users and carers, rather than those of service providers, that should be driving the research review process.

Such a definition of the problem strongly suggests the need and importance of locating both quantitative and qualitative research studies, incorporating findings from both into any systematic review. In particular, qualitative research studies are needed to provide insight into the process of a complex intervention, and/or the perspective of the multiple stakeholders, especially service users and informal carers, on desired and achieved outcomes. They provide an important additional perspective and context to that provided by quantitative, causally oriented research.

Translating Policy Questions into Researchable Questions

The First Topic Area: Rehabilitation

The first topic area for review was agreed as *rehabilitation*. At a policy level interest was dominated by a concern for those with severe and enduring mental health problems and the search for solutions toward enabling people to 'live ordinary lives in ordinary communities'. This coincided with what has been regarded as the main goal of rehabilitation in mental health, namely to ensure that those with severe psychiatric disabilities have the physical, social, emotional and intellectual skills needed to live, learn and work within their own communities.

Translating this high level policy interest into a researchable question required a considerable amount of initial conceptual and scoping work. The challenge was to achieve a balance between defining the topic in a clear and concise manner to enable systematic coverage of the topic, whilst ensuring that the core questions were meaningful and relevant to policy and social care practice.

The topic refinement process comprised a number of steps (Box 1). Such redefinition of the topic area enabled more focused searching for evidence on rehabilitative interventions. The subsequent literature search was then organised around:

- Interventions occurring in a community / home setting
- For adults (aged 16–64) with severe mental health problems
- Where the predominant service delivery was through the multi-disciplinary community mental health team

An extensive literature was generated. This covered not only the two major models of service delivery (case management and assertive community treatment). It also comprised specific services viewed as essential for the rehabilitation of the severely mentally ill (supported employment and social skills training), family interventions and areas of special needs (for example, homelessness and dual diagnosis). The way forward was either to narrow the review brief or to recognise the complexity of the policy interest, separating it into a number

of inter-related review topics. The latter approach was subsequently adopted in the report, providing focus on three aspects:

- Evidence for the effectiveness of the two models of service delivery
- Evidence for the effectiveness of vocational rehabilitation and social skills training
- Review of the appropriateness of the outcome criteria adopted within the research studies

Box 1: Refining Topic One

1. An initial scoping of the literature in terms of:
 - Defining the notion of rehabilitation within social care
 - Specifying its social, as opposed to health care, components
 - Clarifying issues arising for different illness conditions and user groups
 - Identifying the settings in which rehabilitation is carried out
2. A refocusing of the topic as:
 - Interventions with rehabilitation as their focus
 - Defining rehabilitation as enabling an ‘ordinary life’ and quality of life
 - For the user group of adults, with severe mental illness

The Second Topic Area: Prevention

Given the breadth of studies retrieved (n=967), reviewed (n=96) and synthesised in topic one, it was intended to select a more narrowly defined topic whilst retaining significance for policy and practice. Policy interest lay in the area of *preventive services for older people*. This immediately raised two questions for the research team:

1. What does prevention mean within social care in general and in the context of ageing? In particular, what services within the social care arena can be construed as having a preventive emphasis?

2. What are such services preventing, and thus what kinds of outcomes are such services expected to deliver?

At a policy level, at least part of the answer lay in the principles of enabling independent living for older people, as far as possible in the home setting, and giving them a greater individual say in how they live their lives. Relevant types of social care interventions may then centre on preserving the family caregiving effort, enhancing the support given by the neighbourhood and expanding social networks by fostering higher levels of social interactions for older adults. Thus, from a social care perspective, apart from strategies focusing on delaying the onset of chronic illness typical in old age, preventive interventions might include:

- Those designed to increase social support
- Those aimed at preventing symptoms of depression
- Those with the goal of decreasing dependency and maintaining autonomy

In summary, the seemingly, simple policy level question (do preventive services for older people work?) needed to be translated into a researchable question centred around a consideration of what the normal processes of ageing are and ways to support a healthier and better quality of life. However, to enable the completion of the feasibility study, it was further necessary to identify a discrete topic area while still addressing the wider policy level question.

The area of *bereavement* emerged as an appropriate focus. Bereavement represents a significant life event / transition point in the lives of older people. For some individuals the bereavement can have far-reaching and long term negative consequences, with the bereaved person becoming increasingly vulnerable in terms of physical and mental health, their interaction and participation in a wider social environment, and their self-esteem and self-identity. Preventive social care strategies, aimed at preventing so called 'complicated grief', become an important area of interest.

However, even with a tighter brief, in order to understand the nature and purpose of prevention in this area, the literature review needed to embrace three aspects:

- The nature of risk factors, which may affect bereavement outcome and render some older persons vulnerable to complicated grief reactions.
- The types of resources that can affect an individual's experience of this life event
- The nature of coping strategies which can aid adaptation to bereavement
- Interventions that aid or enhance coping with bereavement.

CHAPTER 3

SEARCHING FOR EVIDENCE

Overview of Approach

It is essential that the literature search is carried out in a systematic manner. To this end, the aim was to develop thorough and comprehensive ways of searching electronic databases for the various research designs. The overall approach used to locate the evidence is depicted in Box 2.

A multi-levelled approach is apparent. The searching approach can be represented as three layered (labelled a–c in Box 2). Within each layer, a number of separate stages have to be followed through (labelled 1-9 in Box 2). However, the process must not be viewed as linear, but rather as iterative, moving down and up and back through the different layers or stages.

As the discussion in Chapter 2 has indicated, one of the most difficult tasks was to clarify, refine and narrow down the policy based research question into one that was feasible to investigate. In this regard, the strategy was initially directed by a wide searching strategy, in effect to '*scope*' the topic area. This necessitated search for relevant studies from other countries, with material being identified from a wide range of countries, for example, from China to Sweden, the USA and the UK.

This broad approach was used to contextualise the UK based research studies in a wider international research context and to provide insight into how the research questions for the topic area were addressed in different countries. It is important to note that, for both topic areas, only a minority of relevant studies was UK based. It was thus essential, and appropriate, to include in the systematic review studies from countries with similar cultural settings to the UK. Without them, the evidence base would be poor and insubstantial.

Box 2: Overview of the Searching Approach

- (a) *Using the initial broad inclusion criteria (scoping):*
1. Search a range of health and social care related electronic databases
 2. Search printed health and social care related indexes
 3. Undertake 'relevance checks' on the retrieved abstracts.
- (b) *Refine the inclusion and exclusion criteria (refinement):*
4. Rerun the searches
 5. Continue 'relevance checks' on full reports of the studies
 6. Citation track from identified studies:
 - Check for occurrences of study in citation indexes
 - Check for occurrences of study in citation indexes
- (c) *Continue refinement as necessary, finalising inclusion and exclusion criteria confirmation):*
7. Hand search selected journals
 8. Continue citation track from identified studies
 9. Extend to identify grey literature.

Retrieving the maximum number of potentially relevant references, that is, maximising recall (sensitivity), reduced the possibility of missing worthwhile studies. In consequence, a large number of studies were retrieved. These were visually sifted, judging their potential relevance from the detail provided in the abstract ('relevance checking'). If insufficient information was available for their classification as 'irrelevant' or 'definitely relevant,' the article was obtained and then a decision made.

Sifting through the abstracts arising led to an elaboration and refinement of the inclusion and exclusion criteria. For example for the second topic area, the initial search (prevention, bereavement and older people) led to the exclusion of studies from dissimilar cultural settings, purely medical interventions and ones where widowhood as a social status was the subject of study.

An iterative searching process was thus used, moving through the three stages of scoping, refinement and confirmation.¹ This process also involved refining the inclusion and exclusion criteria and sharpening up the focus of the review question. Thus, a broad strategy was first applied, relevance checks applied to the abstracts emerging, inclusion criteria revised, and the searches rerun. Alongside, the references cited in included studies were scanned to identify further studies. The record of the particular study was reviewed to try to identify why the particular study had not been identified in the search (for example, missing keywords or MESH headings). As necessary, the searches were rerun to see if the study was then picked up.

A range of databases and printed abstract lists were used for the different searches (Box 3). Choice of which to search was narrowed down by consultation with experts. The initial aim was to develop a common strategy to capture the various types of research studies. These would then be supplemented by a combination of free text terms and relevant thesaurus terms to improve the chances of achieving a high recall. However, pilot searches revealed a large variation in the software used by the different databases, and the ways in which their contents were indexed. This necessitated the development of separate strategies for each database. Example search strategies for the two topic areas are presented in Appendix One.

Given the nature of social care research, it was recognised that some potentially relevant evidence may not be published, or made available by traditional means. Attempts were therefore need to be made to access this grey literature via different both specific databases (e.g. Caredata) and research organisations.

¹ This iterative process of searching for evidence bears close analogy with the process of developing a coding system within grounded theory in qualitative research (at least in reverse). In grounded theory, the aim is to generate theory grounded in informants' perceptions, building from initial, user based categories to higher order theoretical categories. In literature searching, the aim is to identify the set of studies on the topic area, building from the general to the particular.

Box 3: Databases and Grey Literature Sources Searched

Databases	Grey Literature²
Caredata	Caredata
Cinahl	LARIA (Local Authority Research in Action)
Cochrane Library	Joseph Rowntree Foundation
Helmis	Local Government Resource Centre
Medline	
Psychlit	
Social Science Citation Index	

Exploring for Overlap

The feasibility nature of the project enabled exploration of whether or not there was any overlap in coverage between the searched health and social care related databases, and the identification of the most important sources to search. If significant overlap was uncovered, this could mean that the searching process could be simplified. This would have considerable benefits in the time and resource limited environment of routine social care practice.

Accordingly, the selected studies in the two reviews were analysed to identify the database(s) from which they were retrieved. Once duplicate studies were removed, the number of studies retrieved by each database, the overlap between databases and the numbers of unique papers retrieved by each database were calculated. Due to licensing restrictions over the undertaking of bibliometric analysis, Caredata had to be excluded.

For Topic One, while 96 studies were included in the source systematic review, 73 were located from the six included databases. Hand searching, citation tracking and retrieval from Caredata located the remaining studies. For Topic Two, this number was 60.

² SIGLE, a database of grey literature compiled by the British Library, was not used as a source of grey literature in the feasibility study.

As Box 4 shows, there was a relatively small overlap between databases for the two topic areas. This indicates that there is no obvious choice of database to search, at least for these two topic areas. Each database found sufficient unique papers to warrant inclusion in the literature search. These findings, which cohere with other research in the area (see Brett and Long, submitted), have important implications for review work in the social care field and health care more broadly. Not only are the search terms used important in determining what studies are retrieved; so too are the databases searched.

Box 4: Potential Overlap between Databases

Topic One: Community Based Rehabilitation

Database	Psychlit	SSCI	Medline	Cochrane	Cinahl	Sociofile
Total No. Retrieved	43	39	27	19	7	7
% Studies Retrieved *	59	53	37	26	10	10
No. Unique Papers	13	15	5	7	2	2
% Unique*	30	38	19	37	29	29

Topic Two: Preventing Complicated Bereavement for Older Persons

Database	Psychlit	Cinahl	Medline	Sociofile	Cochrane
Total No. Retrieved	41	24	10	6	1
% Studies Retrieved *	66	39	16	10	2
No. Unique Papers	22	9	1	1	1
% Unique*	54	38	10	17	0

* to nearest whole number

A key finding of the feasibility study is that users of systematic reviews need to query the range of databases searched and any restriction of the search to one or another database. Researchers undertaking systematic reviews need not only to indicate which databases have been searched, but also why others have not been, and to publish the exact search strategy employed. Careful thought must thus be given to the most appropriate database to search to prevent missing vital information and possibly influencing the results of the review.

CHAPTER 4

EVALUATING THE EVIDENCE

Developing Evaluative Tools to Critically Appraise the Evidence

A specific element of the feasibility study involved exploring the feasibility and value of including different research designs in summarising the evidence base. This necessitated the development of two evaluative templates, one for qualitative and another for quantitative research designs. The template sought to provide an extensive, but informative and workable series of questions both to summarise the core content of the retrieved studies and to assess the quality of the designs in relation to their aims and outcomes.

Two issues were central in the development of the tools. Firstly, there was the notion that the quality of the evidence base could not be determined on methodological grounds alone. Additionally, there had to be a consideration of the relevance of the aims of the study to the review topic; the detail provided on the nature and content of the interventions; and the appropriateness of the outcome criteria and measures, including the range of stakeholder perspectives covered. Secondly, there was the understanding that evaluation by definition involves a judgmental process.

The resulting evaluative tools comprise a set of areas for review and key methodological questions (Appendix Two and Three). The evaluative tool for quantitative studies was based on established methodological checklists for quantitative research, with the addition of fields on outcome criteria and measures. The resultant quantitative evaluative tool was then used to critically appraise any quantitative study, including systematic reviews. For the latter, an additional field was added to record whether and how the study authors had reviewed the quality of the studies included in the systematic review.

In contrast, the evaluative tool for qualitative research studies required substantial development work (see Long and Godfrey, submitted). The intention was to ensure that the criteria employed to evaluate qualitative studies accorded due significance to the epistemology and practice of qualitative research approaches. This implied a consideration and delineation of what should be the criteria for evaluating such research. Primary focus lay

on the plausibility and credibility of the findings in the context of the way the study was undertaken. Crucial to this was an explicit account of how the data was collected such that each component of the research process was made transparent

The first section of the tool was designed to be applicable across all study types. It provides a summary overview of the study, in the form of a simplified but evaluative abstract. Its purpose was to enable any reader of a review, and the reviewer subsequently, to quickly grasp the essential details of a study and its potential value. The overview indicates the purpose of the study, key findings, an evaluative summary of its strengths and weaknesses and possible theory, policy and practice implications, in addition to bibliographic details. The other sections of the tool provide the descriptive and analytical detail underlying this summary overview. Examples of completed evaluative tools for a quantitative and a qualitative study can be seen in Appendix Four and Five.

Choice of which template to use was straightforward except in situations where the research report employed some elements of a qualitative approach within a quantitative design. The most common example was the use of the open-ended interview as part of a survey or pre-post test design. In these instances, the decision over which evaluative tool to use was made by reference to the nature of the data collection and analysis process. Only if the analysis was grounded in the informants' perceptions and located within the context of their own frames of reference was use made of the qualitative evaluative template. Looking more broadly, a research study that truly used a multi-method (quantitative and qualitative), combined approach to explore the problem area, may need to be addressed in a different manner. For instance, a number of templates could be drawn up for the same study, addressing the different dimensions of the topic area that each of the methods addresses.

While the evaluative tools worked well, the work on the second topic area suggested the need for an additional set of questions to be included in the evaluative tools. In reviewing the bereavement literature, there was either a lack of clarity over the theoretical framework informing the work or literature drawing from one of a number of different frameworks. Examples include interventions based on implicit psychological models of stress resolution, the theory of bereavement as a set of stages or as a life transition.

This suggests the need to include detail, and additional fields in the database, on the underlying conceptual and theoretical framework used within a study. Potential questions would include:

- What is the underlying conceptual and/or theoretical framework?
- In what way, if at all, is the framework reflected in the outcome criteria?

These questions would assist the reviewer and user of the database record of the context and contribution of the research study within the wider body of knowledge.

Applying the Evaluative Tools to the Retrieved Studies

The evaluative tools were applied to all studies that met the inclusion criteria for the two topic areas. The database records provided the research team's evaluative, source document for drawing up the synthesis of the research literature.

Looking more broadly, the two databases of critically appraised studies provide an important resource for researchers, practitioners and policy makers in the reviewed topic areas.

Accordingly, the databases are currently being made available via the World Wide Web (<http://www.salford.ac.uk/ihr/hcprdu/cbsc/htm>), alongside the evaluative tools. The expectation is for any user to be able to depend on the database record created, avoiding the necessity of returning to the research report.

In the original tender document, it was proposed to review not only the quality of the research study but also the appropriateness and psychometric quality of the outcome measures used in the study. In both topic areas, this was only partially undertaken. Focus lay on assessing the relevance of the (generally implicit) outcome criteria to the research question and the breadth of perspective adopted. Two things emerged. Firstly, a wide range of outcome measures was being used in the research studies. Secondly, and of critical importance, service and professional viewpoints, to the detriment of the user and carer perspective, dominated the outcome criteria and measures.

Rather than reviewing the psychometric properties of potentially less relevant measures, an underlying problematic feature of the research studies was identified. This suggests an urgent need for research work in developing, in partnership with users, more user and carer centred criteria and measures, not just for research but also for use within the routine delivery and monitoring of social care. At the same time, it remains essential to review the outcome measures in any research study. While this is a time consuming activity (Greenhalgh et al, 1998), this is particularly important in relation to identifying appropriate criteria for routine practice, and the measurement and monitoring of outcomes therein. A relevant checklist is provided in Appendix Six.

CHAPTER 5

SYNTHESISING THE EVIDENCE

Overview of Approach

Given the nature of the guiding question for the systematic review work and interest in both qualitative and quantitative research designs, it was always intended to provide a 'qualitative' narrative synthesis of the evidence. Four criteria were proposed for exploration in the feasibility study (Paper 3, January 1998 Project Advisory Group):

1. *Attributive confidence* (the degree to which a study adds to the understanding of cause by sufficient control of sources of potential bias)³
2. *Intelligibility* (the extent to which the observed effect can be seen to be due to the prior care process)
3. *Adequacy of outcome criteria and measurement* (breadth and appropriateness of outcome criteria and measures)
4. *Contextuality* (the degree to which the observed effect is related to a particular context or setting for the intervention).

As the study progressed, these initial criteria were re-phrased and interpreted in terms that were more specific for the two topic areas reviewed (Box 5). While the strengths and weaknesses of the particular studies (in particular, their attributive confidence and ability to control for sources of bias) were of substantial importance, this was one among a number of key defining features.

³ In research within the health care area, this is commonly related to the 'hierarchy of evidence' model, which places greatest weight on well designed (and properly conducted) randomised controlled trials.

Box 5: Key Criteria in the Synthesis of the Research Studies

- Relevance of the study's aims to the topic area review
- Detail provided on the nature of intervention
- Relevance of the outcome criteria and measures
- Sufficiency of the follow-up period
- Degree of methodological strength/control of sources of bias

Rather than resort to a hierarchy of research design/evidence model, it is the nature of the research question that must be paramount. Thus, in topic one, the review was driven by the outcome domains, seen as most significant and relevant to users and carers. At the same time, greater weight was placed on studies that were well designed and executed (that is, potential biases have been to a greater extent controlled).

Identifying Possible Policy Implications

As well as providing a credible synthesis of the located research evidence for each topic, it was important to draw out the key implications of the evidence for policy makers, and more broadly for social service practitioners. In the current study, only the former was attempted, though not as extensively as was in fact necessary. While policy makers played an important role in the initial identification of the topic area, due to time limitations and communication difficulties, there was limited follow-up during the refinement and confirmation of the precise topic for review. In addition, policy maker input on the submitted draft of the first topic area was limited.

Reflection on this process suggests the need for a multi-phased approach to ensure policy relevance and ownership of the review:

- *Topic clarification:* Begin initial discussions with policy team to clarify the policy dimensions of the proposed topic area, together with researcher access to relevant policy documents
- *Topic refinement and confirmation:* Following scoping of the area, refine topic for review with policy maker input

- *Identification of policy implications:* Provide a firm draft of the systematic review for comment by policy team, with a view to their highlighting potential implications of policy
- *Finalisation of review:* Building on this input, finalise the topic review, including explicit indications of possible policy implications.

Close adherence to this approach should enable the production of a high quality review related as closely as the evidence will allow to the interests of policy makers, and the ownership of the review process by policy makers.

The wider dissemination of the produced systematic reviews to the body of social care practitioners remains to be taken forward. This was outside of the agreed tender for the feasibility study. However, it remains an important need. It could be undertaken, for example, in the form of a bulletin, supplemented by workshops with key stakeholders, including service users. Such workshops would also serve an important research purpose, in providing an opportunity to identify outcome criteria of relevance and priority to users and informal carers.

CHAPTER 6

CONCLUSIONS

This part of the final report has provided insight into the nature of the review process and to address the issue of the feasibility of undertaking systematic reviews of research literature on effectiveness and outcomes in the social care field.

A number of conclusions can be drawn out:

1. *The Policy Question:* If systematic reviews are to aid and inform policy, they have to be able to tackle complex questions. The appropriate guiding review question and answer in the social care field will take the form of: 'This intervention, which comprises a, b and c, ... works ... sometimes ... in the context / under conditions d, e and f ... for combination of problems i, j and k ... as perceived by stakeholders l, m, and n ' (cf. Iles, 1997). Accordingly, the review process is multi-staged. It involves elucidation of the nature of the social care intervention, its multiple components and modes of delivery via a range of service providers. In addition, it involves clarification of the potentially different and multiple perspectives of success (outcome)
2. *Identifying an Appropriate Evidence Base:* In order to gain insight into the complexity of interventions in the social care field and the perspectives of service users and their informal carers, systematic reviews must include evidence from both quantitative and qualitative research studies.
3. *Locating the Evidence:* Moving from a policy level question to a researchable topic demands an iterative searching process, passing through the stages of scoping, refinement and confirmation. This process also occurs alongside the refinement of the inclusion and exclusion criteria. Equally important is the need to search across multiple, rather than a single, databases. Finally, it is essential that a systematic approach is adopted, making explicit how the searches were done, including search terms, databases searched and not searched.

4. *Adequacy of the Evidence Base:* A large number of relevant studies were located for the two topic areas. Its quantity, nature and quality is however variable. For the first area, there were a large number of randomised controlled trials (RCT) and systematic reviews, and a surprisingly small number of qualitative studies. For the second topic area, there was only one RCT, a greater reliance on cohort designs and surveys, together with qualitative designs. Despite, the mixed overall quality of the reviewed studies (see the individual topic area reports for further details), the feasibility study indicates that there is useful research literature that can be drawn together in the form of systematic reviews.
5. *Evaluating the Evidence:* The developed evaluative tools for quantitative and qualitative studies provide an effective way to critically appraise and summarise the studies. Most importantly, the development work has demonstrated the feasibility of systematically appraising qualitative research studies. Further fields need to be added to the evaluative tools to cover the area of the underlying conceptual and/or theoretical model underpinning the research studies.
6. *Outcome Measures:* Both topic areas illustrate the dearth of attention to the outcome criteria that users and their informal carers might see as relevant. Further research is needed to address this, undertaken in partnership with users. Workshops with users based around the findings from these two systematic reviews, would also provide a valuable way to uncover appropriate outcome criteria and more user centred ways for their measurement.
7. *Synthesis of Evidence:* While greater weight must be placed on well designed and executed studies that enhance attributive confidence, the primary consideration must be the nature of the research question. This will lead to the inclusion of other factors in judging the overall contribution of the evidence, in particular, the appropriateness of the outcome criteria.

This study has demonstrated the feasibility, and complexity, of undertaking systematic reviews of policy level questions in social care. This must include close examination of the breadth and relevance of outcome criteria and measures used from the perspective of key stakeholders, and in particular service users and their informal carers. Finally, it is essential to make the review process as ‘transparent’ as possible. A further stage is to disseminate the findings of the substantive reviews and the process of reviewing to social care practitioners and researchers.

REFERENCES

Brettle AJ and Long AF (submitted) Too much information, too little time: is there a need for multiple database searching?

Greenhalgh J, Long AF, Brettle AJ and Grant MJ (1998) Reviewing and selecting outcome measures for use in routine practice, *Journal of Evaluation in Clinical Practice*, 4(4): 339-350.

HCPRDU (1998) <http://www.salford.ac.uk/jhr/hcprdu/ebsc.htm>

Iles V (1997) The communications challenge: it's good to talk ... and be heard! In Meade G (ed.) *Health and Social Services in Primary Care: an Effective Combination*, Financial Times Healthcare: London

Long AF and Godfrey M (submitted) An evaluating tool to assess the quality of qualitative research studies.

Appendix One: Selected Search Strategies***Topic One***

The following annotated strategy (used to locate qualitative designs on MEDLINE) illustrates the terms and approach used in each search.

1. exp interviews/
2. exp 'analytic studies (epidemiology) (non mesh)'/
3. health care surveys/
4. questionnaires/
5. n=1.tw.
6. n-1.tw.
7. structured interview\$.tw.
8. unstructured interview\$.tw.
9. qualitative.tw.
10. or/1-9 *Identifies study designs*
11. schizophren\$.tw.
12. (severe adj mental adj illness\$.tw.
13. affective psychos\$.tw.
14. (manic depression).tw.
15. (bipolar adj disorder\$.tw
16. exp community mental health services/
17. exp emergency services, psychiatric/
18. social work, psychiatric/
19. exp affective disorders, psychotic/
20. exp schizophrenia/
21. or/11-20 *Identifies severe mental illness in community*
22. child\$.tw.
23. aged/
24. 22 or 23
25. 21 not 24 *Removes children and elderly people, to restrict to adults 18-65*
26. rehabilitat\$.tw.

27. (day adj cent\$.tw.
28. (day adj hospital\$.tw.
29. clubhous\$.tw.
30. employment.tw.
31. vocation\$.tw.
32. (meaningful adj living).tw.
33. assertive.tw.
34. team\$.tw.
35. multidis\$.tw.
36. multi-dis\$.tw.
37. exp day care/
38. exp rehabilitation/
39. exp patient care team/
40. *or 21, 26–39 Identifies rehabilitation interventions or interventions by a team*
41. *10 and 25 and 40 Combines aspects of study design, severe mental illness
rehabilitation or teams*
42. exp affective disorders/
43. exp anxiety disorders/
44. exp antidepressive agents/
45. exp antipsychotic agents/
46. exp drug therapy/
47. *or/ 44–47 Identifies non severe mental illnesses and studies including drug treatment*
48. *43 not 48 Excludes non severe mental illness and drug treatments from sample of
possibly relevant studies*

Topic Two

1.	Geriatrics/	661	}	
2.	'aged'/'	183680	}	
3.	'Aged, 80 and over'/'	55345	}	To describe the client group i.e.
4.	Elderly.mp.	14157	}	elderly people
5.	65+.mp.	24490	}	
6.	1 or 2 or 3 or 4 or 5	200983	}	
7.	Bereavement/	428	}	
8.	Death/	567	}	
9.	Widowhood/	89	}	To describe the condition i.e.
10.	bereave\$.mp.	563	}	bereavement
11.	decease\$.mp.	602	}	
12.	widow\$.mp.	291	}	
13.	7 or 8 or 9 or 10 or 11 or 12	1879	}	
14.	6 and 13	582	}	Combines the client group and condition

Key:

/ = MESH heading (key word assigned by the national Library of Medicine to illustrate the ideas covered by an article)

mp = textword (word appears in the title or abstract)

\$ = truncation symbol

Appendix Two: Evaluative Tool for Quantitative Research Studies

Review Area	Key Questions
(1) STUDY OVERVIEW	
Bibliographic Details	<ul style="list-style-type: none">• Author, title, source (publisher and place of publication), year
Purpose	<ul style="list-style-type: none">• What are the aims of the study?• What are the aims of this paper?
Key Findings	<ul style="list-style-type: none">• What are the key findings of the study?
Evaluative Summary	<ul style="list-style-type: none">• Could the observed results have been brought about by something other than the intervention/care process? (Draw together evaluative comments on the study as a whole – strengths and weaknesses – and indicate further research work required, as appropriate, and possible theory, policy and practice implications)

Appendix Two (cont.)

Review Criteria	Key Questions
(2) STUDY, SETTING	SAMPLE AND ETHICS
The Study	<ul style="list-style-type: none"> • What type of study is this? • What was the intervention? • What was the comparison intervention? • Is there sufficient detail given of the nature of the intervention and the comparison intervention? • What is the relationship of the study to the area of the topic review?
Setting	<ul style="list-style-type: none"> • Within what geographical and care setting was the study carried out?
Sample	<ul style="list-style-type: none"> • What was the source population? • What were the inclusion criteria? • What were the exclusion criteria? • How was the sample selected? • If more than one group of subjects, how many groups were there, and how many people were in each group? • How were subjects allocated to the groups? • What was the size of the study sample? • Is the final sample of sufficient size to warrant the conclusions drawn? • Is information provided on loss to follow up? • Is the sample appropriate to the aims of the study? • What are the key sample characteristics? (i.e. in relation to the topic area being reviewed)
Ethics	<ul style="list-style-type: none"> • Was Ethical Committee approval obtained? • Was informed consent obtained from participants of the study? • Have ethical issues been adequately addressed?

Appendix Two (cont.)

Review Area	Key Questions
(3) GROUP COMPARABILITY	AND OUTCOME MEASUREMENT
Comparable Groups	<ul style="list-style-type: none"> • If more than one group was analysed, were the groups comparable before the intervention? In what respects were they comparable and in what were they not? • How were important confounding variables controlled (e.g. matching, randomisation, in the analysis stage)? • Was this control adequate to justify the authors conclusions? • Were there other important confounding variables controlled for in the study design or analyses and what were they? • Did the authors take these into account in their interpretation of the findings?
Outcome Measurement	<ul style="list-style-type: none"> • What outcome criteria were used in the study? • What are the outcome measures used in the study? • Are the measures appropriate, given the outcome criteria? • What other (e.g. process, cost) measures are used in the study? • Are the measures well validated? • Are the measures of known responsive to change? • Whose perspective do the outcome measures address (professional, service, user, carer?) • Is there sufficient breadth of perspective adopted in the outcome measures? • Are the outcome criteria useful/appropriate within routine practice? • Are the outcome measures useful/appropriate within routine practice?
Time Scale	<ul style="list-style-type: none"> • What was the length of follow-up? When was the data on the outcome measures collected? • Is this period of follow-up sufficiently long to warrant the conclusions drawn or to see the desired effects?

Appendix Two (cont.)

Review Area	Key Questions
(4) POLICY AND	PRACTICE IMPLICATIONS
Implications	<ul style="list-style-type: none"> • To what setting are the study findings generalisable? (Indicate if: the setting typical or representative of care settings and in what respects; and if the setting is atypical, is this likely to present a stronger or weaker test of the hypothesis?) • To what population are the study's findings generalisable? • Is the conclusion justified given the conduct of the study (e.g. sampling procedure; measures of outcome used and results achieved?) • What are the implications for policy? • What are the implications for service practice?
Other Comments	<ul style="list-style-type: none"> • What were the total number of references used in the study? • Are there any other noteworthy features of the study? • List other study references
Reviewer	<ul style="list-style-type: none"> • Name of reviewer • Review date

Appendix Three: Evaluative Tool for Qualitative Research Studies

Review Area	Key Questions
(1) STUDY OVERVIEW	
Bibliographic Details	<ul style="list-style-type: none"> • Author, title, source (publisher and place of publication), year
Purpose	<ul style="list-style-type: none"> • What are the aims of the study? • What are the aims of this paper?
Key Findings	<ul style="list-style-type: none"> • What are the key findings of the study?
Evaluative Summary	<ul style="list-style-type: none"> • Could the observed results have been brought about by something other than the intervention/care process? (Draw together evaluative comments on the study as a whole – strengths and weaknesses – and indicate further research work required, as appropriate, and possible theory, policy and practice implications)

Appendix Three (cont.)

Review Area	Key Questions
(2) STUDY, SETTING	SAMPLE AND ETHICS
The Study	<ul style="list-style-type: none"> • What type of study is this? • What is the intervention? • What, if any, is the comparison intervention? • Is there sufficient detail given of the nature of the: (i) intervention; and (ii) comparison intervention? • What outcome criteria are used in the study? • Whose perspective do they address (professional, service, user, carer)? • Is sufficient breadth in perspective adopted?
Setting	<ul style="list-style-type: none"> • Within what geographical and care setting is the study carried out? • What is the rationale and appropriateness for choosing this setting? • Is sufficient detail given about the setting? • Over what time period is the study conducted?
Sample	<ul style="list-style-type: none"> • Who is included in the study (inclusion criteria)? • Who is excluded from the study (exclusion criteria)? • How is the sample (informants, settings, events) selected? • What is the size of the study sample and groups forming the study? • Is the sample appropriate in terms of depth (intensity of data collection – individuals, settings and events) and width across time, settings and events (does it capture key persons and events)? • Is the sample in terms of informants, settings and events appropriate to the aims of the study?
Ethics	<ul style="list-style-type: none"> • Was Ethical Committee approval obtained? • Was informed consent obtained from participants of the study? • Have ethical issues been adequately addressed?

Appendix Three (cont.)

Review Area	Key Questions
(3) DATA COLLECTION,	ANALYSIS AND POTENTIAL RESEARCHER BIAS
Data Collection	<ul style="list-style-type: none"> • What data collection methods are used to obtain and record the data? (Provide insight into: data collected; appropriateness; data availability for inspection / independent analysis) • What role does the researcher adopt within the setting? • Is the process of fieldwork adequately described? (e.g. account of how the data were elicited; type and range of questions; interview guide; length and timing of observation work; note taking)
Data Analysis	<ul style="list-style-type: none"> • How are the data analysed? • How adequate is the description of the data analysis? (e.g. to allow reproduction; steps taken to guard against selectivity) • Is adequate evidence provided to support the analysis? (e.g. includes original / raw data extracts; evidence of iterative analysis; representative evidence presented; efforts to establish validity – searching for negative evidence, use of multiple sources, data triangulation); reliability / consistency (over researchers, time and settings; checking back with informants over interpretation) • Is the study set in a broader context, in terms of findings and relevant theory?
Researcher's Potential Bias	<ul style="list-style-type: none"> • Are the researcher's own position, assumptions and possible biases outlined? (Indicate how these could affect the study, in particular, the analysis and interpretation of the data)

Appendix Three (cont.)

Review Area	Key Questions
(4) POLICY AND	PRACTICE IMPLICATIONS
Implications	<ul style="list-style-type: none"> • To what setting are the study findings generalisable? (Indicate if: the setting typical or representative of care settings and in what respects; and if the setting is atypical, is this likely to present a stronger or weaker test of the hypothesis?) • To what population are the study's findings generalisable? • Is the conclusion justified given the conduct of the study (e.g. sampling procedure; measures of outcome used and results achieved?) • What are the implications for policy? • What are the implications for service practice?
Other Comments	<ul style="list-style-type: none"> • What were the total number of references used in the study? • Are there any other noteworthy features of the study? • List other study references
Reviewer	<ul style="list-style-type: none"> • Name of reviewer • Review date

Appendix Four: Example Completed Evaluative Tool for a Quantitative Study

au: Lund DA and Caserta MS

ti: Older bereaved spouses' participation in self-help groups.

source: OMEGA 25 (1) 47–61

year: 1992

aims of study: To evaluate the effectiveness of self-help groups in facilitating the adjustment process after bereavement.

aims of paper: To describe and compare older bereaved spouses' self-reported assessments of their participation in self-help groups

key findings: Irrespective of short or long term duration of the groups or whether they were professionally or widow led, assessments were positive. Receiving emotional support was seen as the most common need of participants (61%) followed by a desire to help others (17%) and obtaining information about completing tasks (6%). There were no significant differences between groups with respect to participants' perceptions of how well the groups met their main needs or the helpfulness of the support group meetings. Those in the long-term groups, or those attending more meetings, had higher, though not statistically significant, mean scores for how well needs were met and the helpfulness of groups. Mean scores remained stable over time implying that the perceived level of need fulfilment remained strong even with the passage of time. There was a moderate ($r = .3$) correlation between the number of meetings attended and perceived usefulness.

summary evaluative comments: The report on the study is confusing in providing extensive details of the main study of the authors, making it difficult to identify the actual data set reported on in the paper. The main study, and its sub-set, suffers from a number of problems, in particular, the low participation rate (30%) of the target population and its potential bias. While a telephone survey of non-participants undertaken a year later revealed no significant demographic differences, lower stress levels and fewer loneliness problems were also indicated. At the same time, they also had lower perceived coping abilities and lower health ratings than participants. Sample participants may not be representative, raising problems of generalisation.

study type: Cohort (nested within a cohort study with a comparison group)

intervention: Participation in bereavement self-help groups. The groups either met weekly for 8 weeks (short-term condition), or weekly for 8 weeks followed by 10 monthly meetings (long-term condition). They were led either by professionals with master's level preparation and counselling experience (14 groups), or widowed females who had taken part in an earlier study and adjusted to their bereavement (13 groups). On average, there were 6 persons in each of the 27 groups. Emphasis lay on sharing of thoughts and feelings and providing reciprocal support.

comparison intervention:

sufficient detail: Some detail is provided about the training of peer leaders and duration of groups. However, details are not given about the group process such as the type of help and support provided.

what relates to prevention: The effect of an intervention on bereaved persons. The hypothesis is that participation in a self-help group will meet the needs of participants and be helpful to them in adjusting with a bereavement.

geog and care setting: Utah, USA

beginning and duration of study: Not stated; 2 years.

source pop: Older bereaved spouses.

inclusion: Recently bereaved spouses, aged 50 or over, able to speak English, not attending another support group, and *either* with a minimum participation criterion for the short-term condition of participating in at least one-half of the 8 weekly meetings, and for the long-term condition of participating in at least one-half of the 10 monthly meetings *or*, for those in the correlation analyses, partial participation (those attending at least 1 meeting).

exclusion: Those in the main study (N = 339) who did not attend the required number of sessions.

sample selection: 1,150 persons meeting the inclusion criteria were identified from obituaries in local newspapers and contacted within 8 weeks of death of spouse. 30% (N = 339) agreed

to participate in the main study, completing the T1 (baseline) questionnaire, with 175 being assigned to the Self-Help condition and 98 to a comparison/no intervention condition. The eventual study participants reported on here were self-selected by their attendance patterns.

number of groups: 2; Short term = 82; Long term = 52

group allocation: No details are provided of how participants were assigned to groups.

study size: 134, plus 41 'partial' participants

adequate sample size: The sample was large enough for statistically significant differences to be detected.

loss to follow up: 66 (38%) discontinued the main study after completing the initial questionnaire due to the delay in establishing the self-help groups. One of the professionally led groups only met once (no reason is indicated) and its members did not attend another group due to inconvenience or lack of interest.

appropriate sample: As in Utah, only approximately 10% of deaths are not reported in the obituaries, this was a good way to identify recently bereaved persons. However, only 30% of the identified sample agreed to participate. The most common reasons for non-participation were bereaved spouses not being interested (60.2%), too ill (17.3%), too busy (11.8%) or too upset (3.1%). From a telephone survey of randomly selected persons who refused to participate, conducted one year later, while no significant demographic differences were found between participants and non-participants, non-participants reported slightly lower stress levels and fewer problems with loneliness. At the same time, they had lower coping abilities and lower self-reported health ratings. This suggests the possibility of a biased sample. Alternatively, one year later on, the non-participants may have in general passed through the bereavement process/crisis.

sample characteristics: Of the 134 full participants, 76% were women, 90% high school graduates, and 69% had a household income of less than \$20,000. The average age was 68 years (SD = 8). Participants had been married an average of 40 years (SD.= 14) at the time of their spouses death. 48% were in a professional led group and 52% in a widow-led group.

comparable groups: There were no statistically significant demographic differences at baseline.

how confounders controlled: The researchers organised and supervised the self-help groups to maximise control over possible confounding effects.

adequate control:

any / what uncontrolled confounders:

authors take into account in interpretation:

outcome criteria: To meet participants' reported needs, to achieve a high level of participation in groups, and to ensure that the groups were helpful

outcome measures: Participants were asked to select their main need from a list of 5 choices, and to indicate on 5 point scales how well their need was filled and their level of participation.

appropriate measures:

other (e.g. process) measures:

well validated:

known responsive to change:

perspective of measures: User

sufficient breadth: The focus on the user's perspective was highly appropriate.

use outcome criteria in routine practice: These would seem to be useful criteria for routine practice.

use outcome measures in routine practice: In principle, the measures could be used.

length of follow-up: 2 years

sufficient length of follow-up: This would seem a sufficient length of time.

to what setting to generalise: Community self-help groups.

to what population to generalise: Recently bereaved older spouses.

justified conclusions: The authors' conclusion of the positive assessment of the support groups and that it is important to set up self help groups which allow for greater involvement over time and to use both professional and widowed people as group leaders, fits the data.

implications for service practice: Self-help groups are valuable, and can be led by trained non-professional persons.

implications for policy: Establishing bereavement self-help groups.

ethical committee approval: Not indicated

informed consent:

other ethical issues: Providing no support for those in the comparison group is likely to be problematic.

total no of refs: 17

other noteworthy features: The paper includes valuable background information on self-help groups in general (history, helper-therapy principle and philosophy). It points to a number of policy implications of their findings and the need to evaluate whether short-term interventions can be as effective as long-term interventions with limited and scarce resources. The authors also refer to an unpublished conference paper (Lund et al, 1989) which summarises the results of the main cohort, comparison group study. This had shown no differences on behavioural or affective outcomes for the different bereaved self-help support groups.

other study references: Lund DA, Caserta MS and Dimond MF (1989) Effectiveness of self-help groups for older bereaved spouses. Paper presented at the 42nd Annual Meeting of the Gerontological Society of America, Minneapolis, Minnesota.

Appendix Five: Example Completed Evaluative Tool for a Qualitative Study

au: Malone J.

ti: Concepts for the Rehabilitation of the Long Term Mentally Ill in the Community

source: Issues in Mental Health Nursing, Vol. 10, 121–135

year: 1989

aims of the study: To describe the process of working within Community Bound, an innovative, non-professional community programme for the long term mentally ill.

aims of the paper:

key findings: The study identifies and clarifies six empirical categories which underlying the interactions between staff-client and client-clients relationships enabling people with long term mental health problems to live in the community: survival skills; co-operation; hanging out; checking up; backing and supplementing. Differences in approach are also drawn out between lay staff and professionals operating within more structured programmes.

summary evaluative comments: The study adopts a grounded theory approach. Clear links are made between the categories drawn out and the data illustrating those categories. These insights are located within the wider rehabilitation literature in a way which serves to draw out both the similarities and differences between the philosophy and working practices within Community Bound and professional, structured rehabilitation programmes. The data collection process is described in sufficient detail. However, there is no information offered about the process of analysis or how the author developed the categories from the large quantity of data ensuing from over 800 hours of observation and interviews. The description offered is rich in contextual detail and illuminating of the processes involved in delivery and receiving support and care. The findings were also tested out through consultation with experts in community mental health, peers and study participants.

study type: Ethnographic study.

intervention: The philosophy of Community Bound was that persons with psychiatric impairment can be taught to live independently in the community if they have access to daily problem solving assistance from people they know and trust. Staff worked on solving

problems, but did not give therapy; daily contact facilitated extensive follow-up and guidance. All staff were lay persons with no previous experience or training in the area of mental health. Members of the board were mental health professionals and community leaders who provided technical and clinical consultations. The programme was physically located within offices of two large apartment complexes which maintained 24 hour on-site staff; clients lived in the apartments.

comparison intervention:

sufficient detail: The brief description of the process of care provides general insight into the nature of their work if any contrast was to be made with other such programmes. Given the focus of the study on staff and client perceptions and interactions, it is sufficient.

geog and care setting: Community Bound, a private, non-profit supervised independent living programme for the long term mentally ill in Austin, Texas.

rationale for setting: The very low hospital re-admission rate experienced by clients on the programme and the use of non-professional staff, presented an opportunity to examine the process of care within an apparently successful scheme.

sufficient detail: There is a considerable amount of detail provided about Community Bound – its organisation, management structure, staffing, philosophy and client group.

beginning and duration of study: November 1982 to March 1983; five months.

source population: People with long term mental health problems, formerly residents of mental hospitals who no longer needed hospitalisation but did require supervision to sustain community residence.

inclusion: Clients and staff of Community Bound.

exclusion: None.

sample selection: The total population was studied with the exception of two clients who did not wish to participate.

study size: 43 clients and 6 staff.

appropriate sampling frame: The study included all members of the programme.

Fieldwork was both intense (4 hours per day) and deep (over 5 months), given there were only two potential sites. It would have been useful to know whether evening and weekend time periods had been included in time sampling.

sample characteristics: Of the 43 clients in the study period, 90% were white, the average age was 36 (range from 22 to 70), and 56% were male. The average length of tenure in Community Bound was 13 months. Most clients had a formal diagnosis of schizophrenia.

appropriate sample (time, place, persons): The time spent (4 hours per day varying the time of day over 5 months) doing fieldwork (direct observation by sitting in the office, tagging along on errands and appointments), observation and note-taking (30 minutes of observation followed by note taking, fleshed out after each day's observations) is well described.

data collection: Participant observation and semi-structured interviews (with all staff and half of the users, randomly selected) were used. Interviews were taped for full transcription and notes made following each 30 minute observation period. Questions guiding the research indicated the range of areas for study (in particular, client-staff and client-client interactions and services sought and received), though no observation or interview guide is provided.

research role: The observer-as-participant role was adopted. Her purpose was made known to staff and clients. She generally sat in the background but accompanied people on errands, and appointments. The author comments that 'generally' the staff ignored the researcher's presence, unless they needed help or resource information.

adequate description of fieldwork: The process of collecting the data was clear. The time spent (4 hours per day varying the time of day) doing fieldwork (direct observation by sitting in the office, tagging along on errands and appointments), observation and note-taking (30 minutes of observation followed by note taking, fleshed out after each day's observations) is well described.

process of analysis: Analysis of the data was conducted using a grounded theory approach. This involved categorical refinements of the raw data, and subsequently further refinements by consultation with experts in community mental health, peers and study participants. The empirical, conceptual categories are based on and emerged from the data.

adequate description of analysis process: There is little indication of how the mass of data was managed, organised, re-ordered and categorised into the empirically based conceptual themes. With a grounded theory approach, one would have expected the process of generating categories, testing them out, refining the categories to have been described, but it was not.

adequate evidence to support analysis: Sub-categories are identified and occasional illustrative quotes or fieldwork included. These could valuably have been more frequent. It is unclear how the data from the different sources are pulled together, whether they confirm one another or not, or whether the presented evidence is representative. At the same time, the data analysis is informative and convincing.

study findings set in broader context: The findings are contextualised into the broader theoretical literature on rehabilitation .

researcher's potential bias/position: It is unclear, though implied, whether the researcher is a mental health professional. How this might have effected the study is not drawn out. Effects include what was observed and the relationship to and ways of working with staff and clients.

length of follow-up/study: 5 months

sufficient length of follow-up: This seems an adequate time to undertake the participant observation approach.

to what setting to generalise: The author argues for the applicability of a rigorous examination of interactive patterns across community settings. Further research is needed to see if similar categories emerge.

to what population to generalise:

justified conclusions: The concepts generated find support in the data presented.

implications for service practice: The study's findings have potential implications for mental health professionals in terms of the nature of the therapeutic care provided and the process of delivery.

implications for policy: The findings could valuably feed into the content of education and training policy and provision, to encourage staff to identify clients' perspectives and to take these into account in service provision.

ethical committee approval: Not indicated.

informed consent: Explanations of the study were posted in the office. Verbal explanations and written consent secured from all but 2 clients. The latter were excluded from all observational work.

other ethical issues:

total of refs: 19

other noteworthy features: The rationale behind the study appears in its discussion – to provoke nurses caring for the long term mentally ill to re-examine the theoretical basis of their practice and the applicability of the conceptual categories/theory emerging from the study.

other study references:

Appendix Six: Checklist to Evaluate an Outcome Measure⁴

Review Criteria	Key Questions
Purpose	What does the measure aim to do? What does it aim to measure?
Background	Why was this particular measure needed? What was the rationale behind its design
Description	Description of the main domains covered, number of items and subscales, response format, references period and method of administration and scoring
User Centredness	Whose perspective does the measure capture? To what extent does this measure capture user or carer desired outcomes? Is it faithful to the content and form of user and carer views?
Feasibility	How feasible is the measure to use within the assessment, care planning and review process? Consideration of length and ease of administration, scoring, interpretation and feedback of information within social care interaction.
Psychometrics	Does the measure have established reliability, responsiveness to change and validity?
Utility	Can the information provided by the measure become integral to the assessment, care planning and review process? Does the measure involve the user in this process? Does it provide extra information not already available to the care provider?

⁴ See Greenhalgh et al (1998) for a more detailed version of this checklist and its use.